The Palliative Care Option

Although palliative care is one of the least understood service lines within hospitals and throughout the patient community, such programs are growing and adopting multidisciplinary approaches in inpatient and outpatient settings. BY JOE CANTLUPE

The 80-year-old cancer patient wanted to return to his Florida home to die, but the oncologist at the 400-staffed-bed Sarasota Memorial Hospital strongly suggested hormone treatment that required a longer hospital stay.

Eventually, the distraught patient’s family intervened for the move home, much earlier than the cancer specialist would have advised. The hospital’s palliative care team, which focuses on comfort, pain management, and spiritual assistance for the very sick, helped the patient make the transition to the comfort of home, where he wanted to spend his remaining days.

“There was this purpose of trying to make him live a little longer without anybody really listening to this patient,” says Bruce Robinson, MD, MPH, chief of geriatric medicine, and director of the Sarasota Memorial Hospital Medical Education Committee, who recounts the story of the octogenarian patient as an example of the value of palliative care. “The palliative care service sometimes is called in to try to help families and patients achieve their goals when the system has gotten out of hand,” he adds.

Palliative care is among the least understood service lines, not only among patients, but also among hospital staff, including physicians and
nurses, Robinson says. One reason this service confuses some medical staff is because palliative care is designed to help the chronically ill, but not necessarily the terminally ill. Indeed, palliative care teams often focus on patients with multiple chronic conditions who require highly specialized and individualized care.

About 40% of the country’s hospitals have palliative care programs, many of them composed of multidisciplinary teams where social workers and chaplains work alongside physicians and nurses. Some hospitals have established full-fledged programs within departments, while others include teams who work in other areas of the hospital. Another iteration of this care occurs where hospitals use palliative care outpatients programs to improve patient satisfaction.

Ten years ago there were almost no palliative care programs in America. Today, about 63% of hospitals with 50 or more beds have a palliative care team, the Center to Advance Palliative Care reports. In the last five years alone, access to palliative care in the larger hospitals has more than doubled. The center’s 2011 report card shows that the nation gets an overall grade of B for access to hospital-based palliative care, an improvement since 2008 when it received a C.

Despite the cost effectiveness, insurers typically don’t reimburse for palliative care services beyond doctor visits and care related to hospitals. Current healthcare reform proposals include consultation reimbursements.

Michael Nisco, MD, MBA, medical director of the 436-licensed-bed Saint Agnes Medical Center’s hospice and palliative care program in Fresno, Calif., says, “We get more testimonials from patients and families in tremendous distress that palliative care reduces stress on the patient, the family, the nurse, the physician. This is an understanding of what can and can’t be done for a patient, and it is savings in the long run. This is patient-centered care.”

Saint Agnes Medical Center has grown over the past five years with an average of 120 new inpatient referrals each month to an average of more than 400 total patient contacts, including follow-ups each month, according to the hospital.

Many healthcare systems are still evaluating their ROI for palliative care programs, which are relatively new.

At the 230-staffed-bed Gunderson Lutheran Hospital in LaCrosse, Wis., the palliative care program has shown improved fiscal performance and has resulted in “significantly reduced hospital costs,” according to the hospital. In a 2008 report, the hospital cited a cost reduction of $3,500 per patient in

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**EXPANSION EXPECTED**

Over the next two years, what changes do you plan to make regarding your organization's service lines?

- Establish new service lines: 21%
- Expand existing service lines: 26%
- Reduce existing service lines: 18%
- Close existing service lines: 17%
- Consolidate existing service lines: 11%
- No change: 10%
- Multiresponse: 1%

SOURCE: HealthLeaders Media Intelligence Report, Service Lines Grow Amid Strategic Challenges, March 2012; http://content.healthy.com/pdfs/content/277538.pdf

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Overall, palliative care programs have increased 125% over the past decade, according to the American Hospital Association. For hospitals, palliative care is relatively inexpensive because it requires a low start-up investment, with an increasing ROI potential because of projections that more patients—elderly and with chronic conditions—may be suitable for this type of care. Such programs can have an immediate impact on overall resource usage, such as ICU utilization, when patients on palliative care decide to steer away from expensive procedures.

Communities throughout the country are reporting an uptick in palliative care programs, reflecting national statistics on this service. “We have seen a significant growth with the Iowa Health System in developing programs at all affiliate hospitals throughout the state,” says Timothy Ihrig, MD, director of palliative care at the Iowa Health System, which has 10 hospitals in Iowa and one in Illinois. “In Fort Dodge, we have seen a 200% growth in monthly consults over the past few months, and it is still growing.” Ihrig notes that Medi-
billed costs, and a reduction of hospital readmissions for palliative care patients to 6%, compared to 18% in a control population. In addition, the hospital report cited “higher ratings of satisfaction with care from families of patients who die in the hospital.”

In an extensive study in 2006, the Sutter Health Institute for Research and Education, part of Sutter Health in San Francisco, found that palliative care programs at 798-bed California Pacific Medical Center in that city resulted in estimated annual savings of $2.2 million, with daily costs for palliative care patients 14.5% lower compared to usual care patients.

Experts foresee potential for new palliative care programs across the nation. About 90 million Americans are living with serious and life-threatening illnesses, a number that is expected to double in the next 25 years, according to the Center to Advance Palliative Care. The organization’s observation is that most people with serious illness experience inadequate and fragmented care from a variety of doctors. Communication is another issue the organization identifies as problematic, both between doctor and patient, and among the patient’s medical caregivers.

**Success key No. 1: Expanding into outpatient**

Gundersen Lutheran Hospital has initiated a pilot program with the Centers for Medicare & Medicaid Services that enables prospective patients and their families to consider outpatient palliative care—even before they are admitted to the hospital.

“Our goal is to try to enroll patients much earlier, identifying them much earlier in their care,” says Bernard Hammes, PhD, director of Respecting Choices, an organization owned and operated by Gundersen Lutheran that assists organizations and communities in implementing advance care planning practices. He also is Gundersen’s director of medical humanities and chairs its institutional review board and ethics committee.

Essentially, the hospital works with patients and their families to integrate patient choices and direction before a time when the patients can’t make their own medical decisions. Afflicted with complicated illnesses, these patients have progressive diseases that could result in functional decline and frequent hospitalizations and emergency department visits. Many patients’ prognosis gives them two years or less to live—with the anticipation of continuous decline during those two years. Gundersen Lutheran’s program features an interdisciplinary care team dedicated to providing high-quality, seamless medical care, individualized for each patient and his or her family.

Over the past three years, Gundersen Lutheran has enlisted 300 of its palliative care patients in the outpatient program under the advanced care demonstration project with CMS. The program started slowly because of contract problems with CMS, but has revved up, Hammes says. Reviewing patient electronic medical records, Gundersen Lutheran partners with primary care doctors to enlist would-be patients into the palliative care program. The idea is to improve care for patients to reduce readmissions, medical procedures, or pharmaceutical costs, says Hammes.

A team of primary care physicians, nurse care coordinators, palliative care

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**Palliative Care Challenged by Physician Shortage**

**In the past decade,** medical schools have significantly increased their emphasis on palliative care education, but there is a shortage of palliative care physicians.

While there is about one cardiologist for every 71 people experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative care physician for every 1,200 people living with a serious or life-threatening illness, according to the Center to Advance Palliative Care.

According to the December 2010 study published in the Journal of Pain and Symptom Management, the current shortage of palliative and hospital medicine physicians numbers anywhere between 6,000 and 18,000 physicians.

“We need more trained people in palliative care, particularly at the physician and of the spectrum,” says Timothy E. Quill, MD, director of the center of ethics, humanities, and palliative care at the Rochester (N.Y.) Medical Center. “We don’t have enough people to go to places where there is a need. We have been working hard nationally to find funding to train people. It’s an uphill battle.

“Everything is magnified when the patient is in front of us, and we are trying to manage multiple chronic conditions,” he adds. “We need more palliative care specialists to work seamlessly with other health professionals.”

Reasons for the shortages include issues revolving around training for a palliative care physician, who may earn $150,000 to $170,000 annually. Although the number of training programs is increasing, there were only 73 accredited allopathic subspecialty training fellowship programs in the United States. That produced about 66 new palliative medicine physicians each year, according to the Center to Advance Palliative Care. In addition, Medicare funding does not support palliative medicine specialty training.

There have been incentives for young physician to go into palliative care. Quill says. In 2000, the American Board of Medical Specialties approved palliative care as a subspecialty. Shortly thereafter, the Accreditation Council for Continuing Medical Education certified the postgraduate fellowship training program in palliative care.

Medical schools and teaching hospitals are furthering palliative care on the research front, with Mount Sinai School of Medicine housing the Center to Advance Palliative Care and the National Palliative Care Research Center. The CAPC has established palliative care leadership centers across the country to enable interdisciplinary teams to visit peer institutions.

—JOE CANTLUPE
providers, social workers, pastoral care counselors, and other professionals provides the disease coordination services, according to Hammes.

The palliative care team arranges meetings and phone calls with the patients and their families to help identify and manage symptoms and other kinds of medical care. "The goal is to help people with advanced conditions live successfully and with functionality as much as possible in their homes. We make sure they stay on their medications if need be, and prevent unnecessary acute illnesses," Hammes says.

"Let's say someone has heart failure, and under other circumstances, they might call their doctor, who might say, 'Come to the hospital.' Instead, the palliative care team will have an assessment over the phone, there would be someone for this person to call, and help them manage the disease over the phone.

"This model of care targets patients with advanced illness, patients who know they are going to get progressively worse," he adds.

"We feel these patients may see their primary care physicians, but the doctor is often so busy, that the patient isn't given that extra layer of support," Hammes says. "There may be a pain the patient can't deal with. We can dramatically decrease the need at this stage of their lives for this person to come to the hospital, and decrease the number of hospital days. We are offering them a very in-depth discussion about their goals and preferences for future care."

Hammes refers to an extensive study on palliative care, published in 2009 that showed that advance care planning "assists in identifying and respecting patients' wishes about end-of-life care, improves such care from the perspective of the patient and the family, and diminishes the likelihood of stress, anxiety, and depression in surviving relatives."

A more recent study, published in The New England Journal of Medicine last year, showed that getting early palliative care, in addition to regular medical treatment, helped people with lung cancer live three months longer compared to those given standard care. The study focused on 151 patients.

"We believe people want to stay functional in their homes," Hammes adds. "That's the goal. It's not only better for the patient but also turns out to be cheaper for healthcare. You invest this time, it's relatively low-tech and low-cost care, and you prevent three days of hospitalization and you come out ahead. That's not too difficult to figure out. We realize there are limits to how much a patient wants."

**Success key No. 2: Palliative care across service lines**

Whether it's massage therapy or harp music to soothe patients, the 739-staffed-bed University of Rochester (N.Y.) Medical Center includes varied services in its palliative care department, which has 12 private rooms. But a key element of the program involves serving a variety of other service lines, such as neurology and oncology.

"We are involved earlier and earlier in patient care in the hospital. We started in the cancer service. Now we're also seeing heart failure patients and neurological patients, and in the ICU, the full gamut," says Timothy E. Quill, MD, director of the center of ethics, humanities, and palliative care at the medical center.

In addition, the medical center has found that early palliative care interventions can reduce the length of stay for seriously ill patients in the medical intensive care unit by more than seven days without having an impact on mortality rates.

Rochester officials several years ago discovered that proactive palliative care consultation in the ICU has an unintended benefit of financial savings.

In its most recent study in 2007 at the medical center, Rochester found the palliative care intervention saved about 1,400 ICU patient days, at an average of about $450 a day.

"Recognizing these indirect financial effects is critical to ensuring palliative care consultation services continue to expand in hospital settings nationwide," the report said.

By going across service lines, palliative care programs team up their members with other specialists. "Palliative care docs work on a team, and for any individual patient you are highly selective [about] which members of the team you might involve," Quill says.

"Some people might have a spiritual crisis and try to get an experienced chaplain to work with them alongside the medical team. Really, comprehensive care and medical homes are trying to do the same thing," he says, noting that a palliative care team adds expertise in making sure pain, anxiety, shortness of breath, and depression are being addressed.

Over the past three years, palliative care inpatient consultation at the medical center has grown from 250 to 1,000 consultations per year, says Quill.

And Rochester has received The Joint Commission's advanced certificate for palliative care, which recognizes hospital inpatient programs that demonstrate excellent patient- and family-centered care and optimize the quality of life for patients with serious illness.

Beyond that, the hospital system has improved palliative care services to the medical home as well as outpatient care, Quill says.

"It's a no-brainer to make palliative care part of the medical home, to provide comprehensive care to people with serious chronic illness. We are
"Palliative care teams need a broad understanding of many underlying medical conditions and the ability to skillfully address the complex chronic illnesses, in addition to the challenges of pain and symptom management."

Starting a multidisciplinary program that focused on specific ailments for children seemed the perfect solution.

The Iowa program reflected findings of a study that found a palliative care program for children should acknowledge that their ailments are much different than adults’, and the palliative care process might be longer.

Most children in palliative care programs are treated for genetic, congenital, neuromuscular, breathing, and stomach illnesses—much different from an adult palliative care population, which is often dominated by cancer diagnoses. Only about 20% of children had cancer, according to a study in *Pediatrics.*

"Palliative care teams need a broad understanding of many underlying conditions and the ability to skillfully address the complex chronic illnesses, in addition to the challenges of pain and symptom management," according to the Pediatric Palliative Care Research Network and Policy at The Children’s Hospital in Philadelphia. The study focused on 315 patients from six hospitals in the United States and Canada in 2008, with follow-up a year later.

The study also noted that while the typical adult receives palliative care for between one to three months, two-thirds of the children survived past 12 months. "The average span of these patients was longer than many would have expected, and the study results help emphasize that children receiving palliative care services are living and that palliative care is principally about how to best live with grave life-threatening conditions," the report concludes.

After 56 consults the first year, the Iowa palliative care program has been constantly growing, from babies through children reaching adulthood. "We are providing comprehensive management of the physical, spiritual, and social being for children," Petigout adds. The program has been directed to patients with myriad diseases such as cancer, cardiac problems, genetic disorders, and muscular dystrophy.

The palliative care team includes nurse practitioners, outpatient nurses, a child life therapist, social workers, a grief service coordinator, a psychologist, pharmacist, and medical director.

"It's about wellness for these children, but also the entire family," she says.

Palliative care programs for children have shown increased family satisfaction. In a 2009 report to the Agency for Healthcare Research and Quality that focused on a pediatric advanced care team at Dana-Farber Cancer Center and Children's Hospital in Boston, researchers found that palliative care and hospice care helped "ease patient suffering" and helped "parents feel more prepared." At least 92% expressed patient satisfaction in pain management, and 96% in patient support.

Petigout says that palliative care support was illustrated in the case of a 12-year-old girl stricken with a rare and fatal blood disorder. The girl had surprised Iowa University Health System officials—as well as her parents—with talk about wanting to "write a will," recalls Petigout.

The hospital's palliative care nurse worked with the child, for "hours and hours," helping her craft the words she wanted to say, Petigout says. The writings became more than a will—they became a testament about the young girl's life. "That book was a connection for the mom to her [daughter], and has given [the mother] comfort," Petigout says. The girl has since died.

**Success key No. 4: What’s in a name?**

Palliative care experts describe what they term a "branding problem" in which patients, and even hospital officials, confuse palliative care with hospice programs that assist patients in their final stages of life. The confusion between palliative care and hospice care makes some people hesitant to choose palliative care, because they are not at the end of their lives, says Quill.

"What the heck is palliative care? Right away, palliative care has a name recognition issue," Quill says. "Its name recognition is relatively low at 20%. When people learn about it, they ask, 'Why didn't I get that earlier, why isn't that the care for all seriously ill people?' Hospice has a higher name recognition, but it's for people at the end of life," Quill adds.

The Rochester Medical Center has initiated educational programs.
to improve the awareness of palliative care, according to Quill. At Saint.Agnes Medical Center, Nisco says the palliative care team at his hospital has had "clarifying discussions" about the nature of palliative programs with patients and other physicians.

Nisco concedes that when he initially meets patients and their families to discuss his program, he tries to avoid the word "palliative" because of so much misunderstanding. People immediately associate palliative care with hospice. Some hospitals have coined the term "supportive care" to describe their programs, Nisco says.

"There's this assumption that it is just for dying people," Nisco explains. "Despite the success at our hospital, you'll find similar themes. A provider may say from time to time, 'Why do we need that?' At institutions large and small, there's this blind spot. Part of the branding problem is that people think about death and dying. On the contrary, we are promoting life and quality of life."

Such barriers must be overcome, Nisco says, because it stifles the possibilities of palliative care. "People would misunderstand and think the treatment is not working and it means that they are going to die," he says. While some patients who receive palliative care have terminal illnesses, others have serious illnesses, but still can be cured and have longer lives and may benefit by using Saint Agnes' program for pain-management and supportive care during all phases of treatment.

Too often, physicians believe that when palliative care is involved, then suggests treatment has been a failure. "In that way, it makes it difficult to promote the program," Nisco says. Palliative care is an integral part of the evolving standard to provide the best possible care to patients."